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ABSTRACT

This paper presents findings from a 5-year research project involving 50 primarily rural families with infants identified neonatally in birth crisis, or shortly thereafter, as having developmental disabilities. Parents were interviewed to gather information on their perceptions of and experiences with the early intervention (EI) process. Interviews covered medical evacuation of the newborn and mother-infant separation, medical care, referral to early intervention services, insurance and use of private services, family receipt of welfare services, influence of religious beliefs and other family beliefs and fears, and preschool programs. All of the interviewed families had medical "nightmare" stories of inappropriate medical care and advice. Thirty percent received no prenatal care, had no memory of having received, or had conflicting reports on prenatal care. The results indicate that families of young children with disabilities may vary greatly in their experiences and in their reaction to having a disabled child. They may or may not receive or request EI services that could enhance their child's development. In addition, many eligible families do not access available governmental supports. Resources in rural areas may be inadequate and difficult to access. Professionals must learn to effectively communicate and work with families of children with disabilities. In addition, they must be knowledgeable about available resources that can enhance the young child's development. They must also be effective communicators and collaborators with professionals from other disciplines. Finally, professionals must be sensitive to the unique characteristics, strengths, and needs of each family. This sensitivity is critical if effective EI services are to be provided. (TD)

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RURAL FAMILIES AND EARLY INTERVENTION

Introduction

This paper presents findings from a 5-year longitudinal qualitative research project involving 50 families. In-depth interviews were designed to gather information on the perceptions and experiences of parents (and other family members) of infants identified neonatally in birth crisis, or shortly thereafter, as having developmental disabilities. Many of the families studied reside in rural and small town settings. Families whose neonates underwent medical evacuation flights to one of the two urban public hospitals in the state have been dramatically impacted. These and other experiences reflect the unique situation of rural families who have young children with disabilities.

Part H of the Individuals with Disabilities Education Act recognizes the family as the strongest mediating factor in the development of very young children. The law requires that needs assessments be conducted on families of infants and toddlers identified as having a disability if the families agree to such assessments. Written documents in the form of Individual Family Service Plans (IFSPs) must then be developed to address the identified needs. These plans serve as the basis for early intervention (EI) services and are designed to support the families. The underlying assumptions of EI are that: (1) families need and welcome these services and supports, (2) early interventionists know how to determine family needs and develop programs to meet them, and (3) these services enhance the development of infants and toddlers who are disabled or at-risk. Major efforts have been made, using Part H funds, to provide homebased, family centered, transdisciplinary EI services. Implementing this model of service delivery in rural areas is difficult and presents unique problems.

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The main goal of the interviews was to record as accurately as possible the perceptions, feelings, and experiences of parents and family members in the EI process. The first interviews probed the issues of: (a) initial communications with professionals from a variety of disciplines; (b) transitions from hospital to home; (c) contacts from and referrals to additional services and resources; (d) realizations and adjustments to the infant's needs; (e) self perceptions and coping; and, (f) perceptions of assistance received from professionals and interpersonal (extended family, friends, neighborhood, community, other parents, or church) networks. Follow-up interviews further documented the nature of services, supports and/or resources provided to or sought by the families.

This paper provides information on: (1) family selection, interview procedures, and variables coded for analysis; and (2) results unique to rural families including breakdowns in prenatal care that could have prevented birth crises, isolation, transportation difficulties, lack of services or trained providers. The information presented will help facilitate better communication and understanding between family members and service providers. The interview results are extremely important for professionals providing EI services, educators preparing these professionals, and policy makers who wish to improve these services.

In order to meet the intent of the law as well as to provide appropriate EI services, professionals must learn to communicate more effectively with family members. The information in this paper will help providers better understand the contextual variables influencing how families view their identified infant or toddler and assist families to prioritize, articulate, and work towards agreed on program goals.

Information to assist professionals in the early intervention process is included. The data interpretation has focused on early communication between infants and caregivers, the context of families as impacted by cultural and socioeconomic diversity, and how a transdisciplinary family focused program philosophy is perceived by recipients. Many of the families involved in this study are from rural or small town settings, come from culturally diverse backgrounds, are struggling at low income levels, and may be reluctant to seek government support. The information obtained through this study reflects the uniqueness of all families and can help professionals to remember to honor family diversity.

This paper is limited to the families who have participated in the study the longest and for whom there are written individual case studies. These families have three or more interviews transcribed and coded. In

addition, the triangulated data from significant others and records review from EI services have been analyzed. This information has been placed in Folio VIEWS (Folio Corporation, 1993) to help in analysis and theory development.

Subjects

The subjects in this study included 50 families from a variety of backgrounds. Forty-seven percent of the families included in the study are from rural and small town locations. The sample reflects the ethnic diversity of the state. However, there is a small overrepresentation of families from Hispanic and Asian backgrounds compared to the entire state. In years one and two of the study, over sampling was conducted to identify a large number of families to account for attrition over the total five years of the study. Families were identified primarily through mailings conducted in coordination with the EI program and other organizations.

Medical Evacuation

Forty percent of the children in this study were medical flighted to urban hospitals soon after birth. No one but medical staff are allowed to fly with the newborn. Therefore, mothers are left with a poor quality instant photograph of their new baby looking, in one mother's words, "like an alien". Most mothers had emergency caesarean sections. They must stay in the local or regional hospital where they delivered the child. At the same time, the baby is treated in the urban hospital. Fathers and key family and friends are torn between visiting the mother in one hospital and the newborn in another hospital. Rural isolated mothers with transportation and resource problems may not see the infant for weeks after birth. This may impact their ability to "bond" with the child and certainly prevents them from nurturing their newborn during a critical time.

Medical Care

Thirty percent of the families in this study received none, had no memory of receiving, or had conflicting reports (disagreement among immediate family members or significant others) on prenatal care. EI providers must stress the value of preventative care. They may also need to provide basic assistance to families in working with medical professionals. This assistance may take the form of helping families meet medical appointments or being with the family when they talk with medical personnel to help the family members understand the medical information and to help follow up on medical advice.

All of the interviewed families have a medical "nightmare" story. At the time of the medical problem they may not have known how poorly the medical personnel were communicating with them. However, with an historical perspective, the parents of older children (4 to 7 years old) realize they received inappropriate medical care and advice. Stories documented by family and medical reports include:

(1) A young Hispanic mother receiving DHS support repeatedly requested an ultrasound examination because she believed that she was carrying twins although the medical personnel did not agree with her. The ultrasound examination was denied. She had a crisis premature delivery. There were twins, one was stillborn. The surviving twin weighed 14 pounds at three years of age and because of extreme hypertonicity cannot be placed in a sitting position.

(2) The son of a well educated high school special education teacher was born in crisis two months prematurely with a grade 4 interventricular hemorrhage. Perhaps because the mother had such extremely good private insurance, the physicians at the hospital refused to move her and her child to another hospital that had a tertiary care neonatal intensive care unit (NICU). The baby spent six weeks with a massive infection associated with the shunt that was implanted to reduce cranial pressure. He developed a huge blood clot in the brain and had seizures. The shunt did not arrest his hydrocephalus. The mother finally demanded to have him referred to a pediatric neurologist at another hospital. The neurologist at the other hospital with the NICU dissolved the clot, cleared the infection, and replaced the shunt. The child is now three years of age. He cannot walk, has major fine and gross motor problems, and cannot talk. However, he has excellent non-symbolic communication skills and no longer requires seizure medication. His mother says, "He is still underweight but his personality (sense of humor and endurance) are a miracle."

Referral to Early Intervention

Only 31% of the NICU graduates in this study were referred to EI services at the time of discharge from the hospital. Long after they were discharged, twenty-three percent of the NICU graduates received referrals to EI through their pediatricians. Systematic transition procedures must be implemented to ensure that infants and their families are referred to EI programs prior to their release from NICUs. It is important to have a person familiar with Part H services working in the NICU to ensure smooth transitions. In addition, states need more effective child find processes: Interagency Coordinating Councils (ICCs) must have effective public awareness activities; medical personnel need continuing education to

enhance their knowledge of EI services, improve their ability to work with other professionals, and to communicate effectively with families; and all pertinent clinics and health department offices should have EI information and referral forms available for families. Personnel should adopt a "when in doubt" attitude to access services as opposed to the prevalent reassuring attitude response that the child will "grow out of this problem".

Insurance and Private Services

Some families in this study were found to be eligible but did not want EI services. Other families may have preferred to use private providers. One family of a child with Down Syndrome, who is now a toddler, take him to another state for very costly and empirically questionable consultation that is not covered by insurance. Other families with sufficient means pay for services themselves or have very comprehensive insurance policies that cover extensive services. The future development of these children will be fascinating to explore. Private consultants and therapists tend to work in isolated contexts on their own discipline specific domains. Often, these therapists provide services without a family centered or transdisciplinary perspective. This model of EI is the opposite of the home-based, transdisciplinary, and family centered model used in the state EI efforts. EI providers need to accept that families may seek services beyond those provided by the EI program.

Government Support

EI providers must be aware that they will be working in home environments that may seem inadequate from a middle class suburban perspective. One half of the families in the study receive support from the Department of Human Services. Of the families in the study that are eligible for the Special Supplemental Food Program for Women, Infants, and Children (WIC) only 46% are receiving this governmental support. Only 50% of the eligible families receive Aid for Families with Dependent Children (AFDC). EI providers should recognize that families may not receive and may not want the governmental supports for which they are eligible. When less than half of the eligible families receive public assistance it may be that some of these families are too proud to accept help. The EI providers may wish to help the families question this perception in a sensitive manner.

EI providers should recognize that only approximately half of the eligible families seek public assistance. Resource Coordinators need to be familiar with the required paperwork, policies, and processes for obtaining public assistance. They need tactful strategies for acquiring information,

explaining the various avenues for assistance, and being able to help parents through the lengthy delays they may encounter in the process. Also, EI providers must be prepared to help apparently disorganized families to understand the required documentation and how to maintain that information in order to access and sustain governmental support. Families may need to be supplied with organizing materials such as notebooks, resource manuals, calendars, day planners, folders, etc. to keep documents and information organized.

It is also important for EI providers to understand and anticipate the diversity of family abilities in accessing assistance. Some families are very capable of working the system. These families may irritate some providers. For example, some providers may believe that if the parent spent more time with the child and less time "hustling" public assistance the child could meet some of "our" goals faster. This is inappropriate and judgmental. Such an attitude will not help in developing rapport and supports for families.

Individual Family Beliefs

Some families with fundamental religious beliefs have chosen to home-school their children. Certain family members may believe that having a child who has a disability is a test or a curse. Parents may perceive each new piece of information they receive concerning the identified child's disability as a greater test (or punishment for past sins). They may concentrate on prayers for healing rather than working on adaptive responses and the development of supports for their child's needs. It is important for EI providers to help these parents realize that the provision of special services is important and can be consistent with their personal beliefs.

Some families refuse to place their child in school-based pre-kindergartens because they are ashamed and fearful about having their child on a special bus. Everyone knows who the little yellow buses serve and they do not wish to have that stigma on their child or themselves. EI providers need to understand that each family has its own unique beliefs that may influence whether and how they access special services.

Older Children

The state in which the study was conducted does not serve at-risk infants and toddlers. Some children who were at-risk as infants and toddlers and did not receive services have developed delays that qualify them for services as they aged. This has resulted in some three to six year old children becoming eligible for IDEA Part B funded services. The

researchers for this study have not identified a large or representative group of these children because referrals to the research project primarily come from the EI program. However, some subjects have been identified in LEA classrooms where older research project subjects are placed. Others have been identified through parent networking. If further funding is secured these children, as well as those who received EI services, will be tracked longitudinally and developmental outcomes with concurrent changes in family functioning will be examined. This will be especially interesting when exploring long-term effects from time and intensity of EI services the children received.

The researchers are now following seven and eight year old children who were identified as having developmental disabilities in 1988. The longitudinal nature of the study has helped to raise and explore some interesting issues. For example, some young children who received early intervention have progressed so well that they were not eligible for public school services when they became three years old. The development of these and other children who were, but are no longer, eligible for special services should be monitored to ensure that possible future developmental delays are detected early or prevented. The probability of regression with underserved preschoolers with disabilities is substantial and the longitudinal data set documents the serious nature of these problems.

Some local education agencies do not have preschool programs. In addition, the state in which this study was conducted does not serve three year old children in Headstart programs and prefers to target children with mild disabilities to meet the 10% mandate for serving students with disabilities in Headstart programs. In these situations, when preschool programs are not available, the schools may provide homebound services. In some rural areas these services may be sporadic and infrequent. Rural families may become reluctant to use these inadequate services. In addition, in rural isolated home settings, the children may not receive socialization experiences with other children who are not disabled. If a public school has a pre-kindergarten and will accept the identified child, the probability is high that the program will be self-contained and only for children with disabilities. In these situations, families do not become familiar with more inclusionary models of service delivery and may not value inclusive programs as the child ages. They may come to believe that self-contained programs are better, more protective, and the only appropriate placement choice. Professionals should be aware that limited or segregated early childhood services may have long lasting influences on the perceptions of families toward special services. The provision of services that incorporate the most feasible application of promising early

childhood practices may set the stage for the enhanced development of children with disabilities throughout their lives.

Summary

The results of this qualitative longitudinal study indicate that families of young children with disabilities may vary greatly in their experiences and in their reactions to having a child with a disability. They may not receive or request EI services that could enhance the development of their child. In addition, many families do not access available governmental supports for which they may be eligible. Resources in rural areas may be inadequate and difficult to access. It is critical that professionals working with families of children with disabilities learn the necessary skills for effectively communicating and working with families. In addition, they must be knowledgeable about the available resources that can enhance the development of the young child. They must also be effective communicators and collaborators with professionals from other disciplines. Finally, professionals must be sensitive to the unique characteristics, strengths, and needs of each family. This sensitivity is critical if effective EI services are to be provided.

Reference

Folio Corporation. (1993). Folio VIEWS personal electronic publishing software: User's guide, Version 3.0 for the Macintosh environment. Provo, UT: Author.